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Reasons to Donate

The Perspectives of Dialysis Patients on Kidney Donation

by

Sarah Elizabeth Dixon
MPH (University of California, Berkeley) 2002
BA (University of California, Santa Cruz) 2000

A thesis submitted in partial satisfaction of the requirements for the degree of

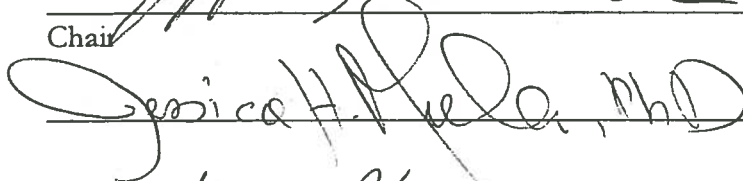
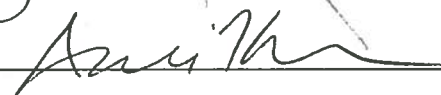
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Sarah Elizabeth Dixon

Table of Contents

Part 1: Reasons to Donate.....1

The Perspectives of Dialysis Patients on Kidney Donation

Background 2

Methods 5

Results 7

Life on Dialysis 9

Talk of Transplant 11

Incentives for Organ Donation 11

Knowledge – Empathic Education and Prevention 18

Influencing Factors 20

Discussion 20

Limitations 23

Conclusions 23

Appendices 25

References 31

Part 2: Reframing the Debate.....32

Adding the Perspectives of Dialysis Patients

Limitations to the Donation Model & Proposals for Change 33

The Debate on Incentives for Organ Donation 37

Altruism vs. Commercialization 39

Autonomy vs. Beneficence 42

The Current Reality of Organ Transfer 47

Conclusions 48

References 50

Speaking to the Process

This was an emotionally challenging project. There were times I wanted to avoid the clinic, guilty of walking away with two healthy kidneys, especially after having talked to someone for an hour about their desire for a transplant. And although I believe accountability to participants is a good thing, the amount of stress I experienced over the writing for fear I would get it wrong was a little excessive. From data collection to the written work, every possible problem a qualitative researcher could experience, I made sure I found a way to go through it.

I am truly humbled by following list of people to acknowledge. I would like to thank: Mario Corona, MD, the Study Participants, and the Dialysis Clinic Staff. My Thesis Committee: Jeff Burack, MD, MPP, B.Phil, Jodi Halpern, MD, PhD and Jessica Muller, PhD. Thesis Helpers: Coco Auerswald, MD, MS, Tom Boyce, MD, Anne Cashmore, Lee Kaskutas, DrPH, Judith Little, PhD, Guy Micco, MD, Ann Russ, PhD, John Swartzberg, MD, FACP, Paul Shen, MPH, Marwa Shoeb, Marcela Smid, Ann Stevens, MD, Joel Wickre and Jenny Wilson. The Ladies Who Let Me Talk: Nina Green, Jessea Greenman, Dyanna Sweeny and Mary-Rita Algazzali. My Classmates & Friends. My Family: My Mom & My Dad and My Guys: Scot, Evan, Jesse, Weston, Alec.

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PART 1

Reasons to Donate

The Perspectives of Dialysis Patients on Kidney Donation

INTRODUCTION

Organ exchange is a controversial and ethically laden topic. The current US system of organ donation, a system that has been in place for the last 30 years, is rooted in our most basic assumptions regarding right and wrong. It is a system founded on deeply held ideals of altruism and the avoidance of exploitation. It reflects our social values of solidarity and commitments to equality, liberty, and the sanctity of the human body. However, it is a system that has failed to keep up with an increasing organ shortage, one that currently leaves over 65,000 Americans waiting for kidneys.¹ This shortage of transplantable organs fuels the debate over offering incentives for organ donation. As we will see in Part 2 of this paper, the debate over incentives revolves around the tension between the need to increase organs for donation and the conflicting desire to retain our commitment to donations based in altruism. Although this debate has included a number of perspectives from fields as diverse as anthropology, bioethics, and economics, it has left out the perspectives of those who would be most directly affected by change to our system of organ donation and transplantation – the dialysis patients.

It is not clear why dialysis patients have been excluded from the discussion. One possible explanation is that they stand to benefit from increasing the supply of kidneys for transplant. Perhaps there is an expectation that they will favor incentives because they have something to gain. Regardless of the reason, I believe this debate is incomplete without adequate representation from the debated populations. My research project initially began with the purely descriptive question, “What are the perspectives of dialysis patients on incentives for kidney donation?” However, it became clear when I discussed this project with my thesis advisors that my motivations ran deeper. I was not just looking for the perspectives of dialysis

patients on the matter, but rather, I wanted to explore how these perspectives were shaped. I believed that in this more interpretive question we would begin to understand the real value to including their perspectives. It is with this in mind that I set out to conduct a qualitative study that not only describes dialysis patient's views on the commercialization of kidneys, but also analyzes *how* the lived experience of individuals on dialysis shapes these perspectives. Through this study I hope to bridge the gap between policy, bioethics theory, and people's lived experience.

My hypothesis going into this project stemmed from the idea that our experience – our individual life's circumstance – has the potential to change our ethical framework, sometimes fleetingly, sometimes permanently. Put simply, I assumed that being on dialysis would alter an individual's views on kidney donation compared to someone without such experience. I was curious to know how a long wait on dialysis by someone who thought about a kidney transplant daily differed from that of someone who does not really care either way if he or she received a transplant. Other factors, in addition to time on dialysis and desire for transplant that I thought might be related to an individual's view on kidney donation were quality of life on dialysis, donor preferences, and prior thoughts on the current system of organ allocation.

I was humbled to find no such patterns. Although my hypotheses generated a valuable interview guide, they were not supported by the data. I was wrong to think that the data could predict who might support incentives, but right to think that the experiences of dialysis patients would contribute to this debate - at the very least by providing a missing viewpoint, and at most, by asking us to think differently.

BACKGROUND

As of July 2005, there were more than 65,000 Americans waiting for kidneys. The expectation is that only about a quarter of them, approximately 15,000, will receive a transplant within the next year, and 6,000 will die waiting.¹ The numbers swelling the waitlist continue to

outpace the number of performed transplants, creating a sense of chasing after a rapidly moving target. The continued organ shortage has led to a search for a better system of procurement. This task has proven to be nearly impossible and has forced the transplant profession and other interested parties to reframe the ethical discourse concerning compensation for organs. The tides are changing. What used to be passionate rejection of anything but uncompensated donation has slowly been replaced by an open debate of plans to offer incentives, including financial rewards.

The debate around organ commercialization is complex and expansive, encompassing various perspectives ranging from anthropologic to religious, philosophical to medical, political to moral. Will commercialization exploit individuals in greatest need, violate human dignity, and harm special moral goods such as liberty, equality and justice? Or does forbidding the sale of organs for transplant itself exploit some benefit to others, violate basic dignity, and lead to significant moral harms?² Regardless of how the issue is approached, at the heart of the debate is the core conflict around the buying and selling of human organs. The following two quotes by philosopher Bob Brecher and transplant surgeon K.C. Reddy illustrates two opposing points of view:

However much the Turkish peasant who sold a kidney may have needed the money he was paid; however genuinely he may have wished to exercise his autonomy in this enterprising venture...however sincere his wish to benefit his family with the proceeds, and however great their need; nevertheless what he did was wrong.³

I am convinced that if I had to feed my child and could obtain enough income to buy a substantial food supply by selling a kidney, I would be terribly distressed with anyone who had the nerve to tell me I should refrain because of some theoretical principle about the repulsiveness of selling my body parts.⁴

The idea of reducing living human tissue to a commercial good and the thought of someone willing to undergo “unnecessary” surgery evoke an understandably emotional reaction. They are hard to comprehend.

The survey literature has focused on the general public or on health professionals, but with a few exceptions has not looked at those who will be directly affected by changes in the

transplant system, namely potential donors and recipients. A 1990 public opinion survey conducted by the National Kidney Foundation found an even split between those who would favor and those who would oppose some form of donor compensation.⁵ It should be noted that most of the positive responses in this survey were from younger respondents. According to other opinion polls, the approval for financial incentives programs varies from 12% to 52%.⁶

One study done by Jasper et al, examined the attitudes of three groups of healthcare professionals – transplant surgeons, transplant coordinators, and critical-care-nurses – towards the current system and to alternative policies.⁷ Their findings are summarized as follows:

1. All three professions believed the current altruistic policy to be morally appropriate; alternative policies offering non-monetary incentives or indirect monetary incentives to be morally appropriate or morally neutral; and alternative policies offering direct or indirect monetary incentives to the donor family to be morally inappropriate.
2. All three professions believed the current policy of organ donation to be at best only moderately successful. All three professions judged at least 5 of the 6 proposed alternative policies to be likely to increase donation relative to current policy.
3. A policy offering donor recognition had a significantly higher percentage of advocates in each profession than did any other policy, with at least three fourths of the respondents in each profession deciding that this policy should be implemented despite its relatively low mean likelihood-of-donation ratings.

This study is consistent with a mixed, yet overall increase, in support of change to our current system of organ donation. The authors note that the generally increasing support for incentives could reflect the observation by healthcare professionals that the current policy has not been and is unlikely to ever be adequate.

One influential study, conducted by Madhav Goyal and colleagues, documented the health and economic effects of selling a kidney on the lives of over 600 people living in poverty in India.⁸ They concluded that among paid donors in India, selling a kidney does not lead to significant long-term benefit and may be associated with a decline in health. This research is often cited as proof that the exchange of organs for money cannot be separated from economic inequality and that the poor still remain poor.

Another study specifically targeted dialysis patients and their views on kidney commercialization. This study by Ashwini Seghal and colleagues was a quantitative analysis of patient responses to questions about options for incentivizing kidney donation.⁹ These questions were meant only to establish what these patients thought and not why they had come to those conclusions. The authors found that there was a lack of consensus among study participants about whether or not financial incentives should be provided for kidney donation. Still, without understanding the factors that influence their responses, this study is limited in its interpretation and application.

There is little attention paid to the internal debate, motivations, or concerns of the affected parties. Most notably, the perspectives of the potential recipients—those people currently on dialysis, waiting for a kidney—are absent. The following study attempts to address this gap through a qualitative analysis. My goals are threefold: to describe dialysis patients' views on various incentives for kidney donation, to analyze how the lived experience of dialysis patients shapes their perspectives, and to demonstrate the value of more thorough representation in the ethical discourse surrounding kidney donation.

METHODS

Design

Twenty-five semi-structured interviews were conducted with patients undergoing hemodialysis. The interviews, which lasted for approximately one hour, were audio-recorded and transcribed. The interview guide included questions from the following domains: Life on Dialysis; Talk of Transplant; Views of Organ Donation; and Incentives for Organ Donation.

The following nine incentives asked in the interview guide came from the literature:

- Regulated Market – with a central purchasing system to provide counseling, reliable payment, insurance and financial advice. The same amount of money would be given to each donor.
- Tax Credit or Tax Refund – for the donation of an organ.

- Funeral expenses – provides partial reimbursement for funeral expenses for families of deceased donors.*
- Charitable Contribution – a set amount of money from a donation would go to a charity of the donor's choosing.
- Medical Leave – a 30-day paid medical leave for employees who donate an organ.
- Donor Insurance – provides life and disability insurance for all living donors.
- Medal of Honor – a donor medal of honor would express appreciation on behalf of the American people to living donors and the families of deceased donors
- Preferred status – if someone donates or intends to donate (by signing a donor card), they would receive points that would increase their chance of receiving an organ from the waitlist, should they need it in the future.
- Organ exchange – an exchange of organs from two living donors or from one living donor and one deceased donor.

There was time at end of each interview for participants to add additional thoughts (see Appendix A for complete Interview Guide).

Sample and Setting

All 25 interviews took place at one dialysis clinic in the East Bay. Patients eligible for study participation were: adult (age 18 and older), fluent in English, and with dialysis-dependent end stage renal disease. I chose only to interview patients undergoing hemodialysis, because it was the only form of dialysis provided by this clinic and because in-center hemodialysis is the most predominant treatment method (92% of dialysis patients nationally).¹¹

A purposeful sampling method was used to select study participants. This method was used to approach participants varying in age, gender and ethnicity. Potential participants were approached during their dialysis sessions and invited to participate in the study. I attended all possible shifts over the 9-month period of data collection. Attempts were made to recruit patients equally from the morning, afternoon, and evening shifts. Patients provided written consent before the interview and were offered 25 dollars for their time. Confidentiality was maintained by changing the patients' names and by removing any other potentially identifiable data from the transcripts. Quotes were edited for brevity and clarity. This study received

* Organs are obtained from living donors or newly deceased donors, deemed "brain dead." The accepted definition of brain dead refers to the whole brain, meaning the individual has sustained irreversible cessation of all functions of the entire brain, including the brain stem.¹⁰ When donors are deceased, the donation comes from that individual's family.

approval from the University of California, Berkeley, Committee for the Protection of Human Subjects.

Analysis

The transcribed interviews were analyzed for themes and patterns using a grounded-theory approach.¹² I created case notes for each study participant, coded the case studies, and used my notes to generate thematic categories. All 25 interviews were then re-coded using the NVivo qualitative data analysis software program and analyzed for emerging themes.¹³ A codebook was generated from the case notes, themes and interview guide (see Appendix B for Codebook). Microsoft Excel was used to explore relationships between potential influencing factors, including demographic information and participant responses (see Appendix C for example Spreadsheet of Influencing Factors). I used Excel to visually identify patterns using color codes. For example, I took the 14 participants who said yes to 7 of the 9 incentives, labeled them red and then looked for patterns using variables from the demographic questionnaire as well as the interview guide. The variables were color-coded along the spreadsheet, explored independently and in combination with others. I used the same technique to look for patterns among participants who said yes to particular types of rewards. When no gross patterns were identified visually, further statistical tests seemed unnecessary.

RESULTS

Participants

Interviews were conducted with 14 men and 11 women. The majority of participants were African American (60%) between the ages of 50 and 69 (44%) years with an average household income under \$15,000 per year (60%) (see Table 1). Although time on dialysis ranged from two months to over 13 years, most of the participants had been on dialysis between 1-5 years (52%) at the time of the interview. Most of the patients (40%) developed end stage renal failure from high blood pressure. Four of the study participants previously had a kidney

transplant. The characteristics of this study population mirrors the national population of dialysis patients in their age distribution and gender, where 54% are male between the ages of 50-69. However, unlike this study population, 54% of the dialysis patients nationally are Caucasian and only 37% African American.

Table 1: Characteristics of Study Participants

	N	%
Gender		
Male	14	56
Female	11	44
Age		
20-29	2	8
30-49	9	36
50-69	11	44
> 70	3	12
Ethnicity		
African-American	15	60
Caucasian	4	16
Asian/Pacific Islander	2	8
Hispanic	2	8
Other	2	8
Education (completed high school)	17	68
Marital Status		
Not married	20	80
Married	5	20
Employed		
Yes	4	16
No	14	56
Retired	7	28
Income (average household yearly)		
< 15,000	15	60
15-29,000	5	20
30-44,000	1	4
45-74,000	2	8
> 75,000	2	8
Time on Dialysis (mo)		
< 12	3	12
12-59	13	52
> 60	9	36
Original Disease*		
Hypertension	10	40
Diabetes Mellitus	7	28
Other	10	40
Don't Know	3	12
Previous Transplant		
Yes	4	16

Themes

Analysis of the first two domains – Life on Dialysis and Talk of Transplant – provided a preliminary understanding of potential motivating factors. For most of the study participants, dialysis was described as an unpleasant experience, one which had a significant negative impact on their lives. A kidney transplant, on the other hand, was discussed as something that offers hope for a better life. Eighteen of the twenty-one eligible patients were waiting for a kidney transplant at the time of the interview. Analysis of the incentives domain generated two important themes of fairness and appreciation. The most significant finding of this study, the theme of empathic education, came from the analysis of the incentives domain as well as in the patients' additional thoughts.

Life on Dialysis

Hemodialysis treatments usually last between 3 and 5 hours and are done three times a week. Although every patient is affected differently by his/her time on dialysis, common threads emerged in the interviews. There were few for whom dialysis had a positive impact. Although many were grateful for this life-saving technology, most patients experienced a deteriorating quality life directly attributable to their treatment.

Side effects were mentioned by most of the participants. These included pain associated with the stick of a needle, fatigue, nausea, vomiting, cramping, muscle weakness, dizziness and an overall decrease in energy. Glen describes the physical effects of dialysis in the following statement, "It's a hateful process. You don't sleep very well at night. Your energy level is usually down. You're nervous. Your limbs tend to be affected. You don't walk so well."

Others commented:

The first year on dialysis wiped me out totally. My blood pressure used to drop precipitously. I mean like down to 85 over 40 or 85 over 50. I passed out once, got up and started to walk outta here. Next thing I knew I was looking up at a fireman. (Vick)

I used to expect to come to dialysis to get real sick. By cramping. You'd be feeling OK, and the next thing you got these cramps. That can destroy your day. You may feel

good right here and then maybe get home and have a couple of cramps, which is no good. (Martin)

Many patients stayed home after their treatment, naming their day “a dialysis day,” meaning they should not expect to do too much. Most participants described feeling fatigued, but a few acknowledged it was fear that limited their activity. As stated by Dwight, “Sometimes after dialysis you have these palpitations, and it causes you a great deal of discomfort... You get so afraid, you may end up calling the ambulance.”

Dialysis becomes a lifestyle. Dwight described the dialysis machine as an “umbilical cord.” Gary said that dialysis has clipped his wings, that he was no longer able to travel the world. The treatment itself literally binds patients to their beds and to the clinic, limiting their ability to work, to attend school, to travel, to build relationships and to maintain them:

I have not been able to do any work since I’m on dialysis. Any gainful work. Although I try, but it doesn’t work... And at home most of the time I spend on computers, doing some statistical work or just reading. That’s all I do now. (Amit)

Then the other thing is coming here three times a week, three and a half hours running on the machine. That’s taking away something you would want to do. Like, for instance, I want to go back to school, culinary arts. (Latasha)

Dialysis also has an emotional impact. Life at the clinic is not a private, quiet, or inspiring experience. The beeping of the machines and the cries, moans and snores of other patients make the experience of dialysis audible, as these participants observe:

You can’t just walk through that door, you know, like you’re coming to a doctor’s appointment. I think you really have to prepare yourself for this because there’s people in here worse off than you, and you ask yourself, “Is that me in the future?” (Clydell)

I can kinda tune out all these beeps, and sometimes people are shouting or moaning or crying or, you know, they’re having cramps or difficulties, and it’s kind of upsetting if you’re taking all that in... (Gary)

‘Cause we are all chronics... we’re not going to change very much. Just get worse. You know that statistic, don’t you? One in four die. Each year. I’ve seen it here. Again and again people just disappear. That’s very disheartening too. (Glen)

For some it is a reminder of their own good fortune; for others it is a fearful prediction of where this treatment may lead without a transplant.

Talk of Transplant

The majority of the dialysis patients I interviewed (21/25) were interested in a transplant. Three of the four patients who previously had a transplant were interested and waiting for another one. For most of the study participants, a kidney transplant was something to hope for, something worth the wait. Many of the patients used the term “free” when referring to a transplant. Latasha said, “It’s like you are free again. You can do whatever you want to a certain extent.” Wesley was hypothetically thanking a donor when he said, “Thank you for giving me another chance at life, another chance to live. Thank you for giving me my freedom back.... Thank you. I don’t need this any more.”

When asked how often he thought about a kidney transplant, Lee replied:

You think about it when you’re driving on the road and you see someone totally out of control, reckless. You think about it when you don’t feel well. You think about it when climbing them steps just wore you out. You think about it when you want to play ball with people. You can’t... You think about it from every situation that goes around. But you can’t think of it as if it doesn’t happen, I won’t have a good life.

Richard was told he had three years to wait. At the time of the interview it had been 3 years and a couple months. He commented:

I think about it just about everyday. But it doesn’t bother me as much now because I’m at that time, and I’m feeling a lot better about it because of the time. And I guess as time goes by and I haven’t received one, like what they said, then I’ll probably lose a little hope. But I still have hope.

Anna, on the other hand, who had just been told she that she has a donor, said, “It’s overwhelming. [Laughs]. I feel like it’s 20 years from now that I have to wait. I’m just so excited. I should be so thankful because a lotta people in here are just waiting.”

Incentives for Organ Donation

When asked about incentives for organ donation, all 25 dialysis patients agreed to at least one of the nine possible choices. The nine incentives asked about in the interview guide came from the literature (see Appendix A for all nine choices). The following four incentives were picked for analysis because they serve as illustrative examples of the different types of

compensation, ranging from completely non-monetary, like a medal of honor, to a regulated market, where kidneys are given in exchange for money.

- **Medal of Honor** – a donor medal of honor expressing appreciation on behalf of the American people to living donors and to the families of deceased donors.
- **Preferred Status** – if someone donates (or intends to donate), they would receive points that would increase their chance of receiving an organ from the waitlist, should they need one in the future.
- **Funeral Expenses** – provides partial reimbursement for funeral expenses for families of deceased donors.
- **Regulated Market** – with a central purchasing system to provide counseling, reliable payment, and financial advice. The same amount of money would be given to each donor.

The following chart summarizes the participants' responses:

	Yes	No	Mixed	N/A
Medal of Honor	17	7	1	0
Preferred Status	17	8	0	0
Funeral Expenses	20	4	1	0
Regulated Market	14	8	1	2

Only one participant said he was not in favor of any of the four incentives. The rest of the negative responses were spread among the group of study participants.

Medal of Honor. The majority of participants (68%) felt that there was nothing objectionable about a potential donor receiving a medal of honor. Richard, who agreed with every reward, commented:

Me personally, I probably wouldn't want to let people know that I did all that just to get a plaque and stuff like that. But if that's the way they want it, yeah. Why not? A lot of people give to charity or something anonymously and don't want to know it and some do.

However, there were some enthusiasts. Wesley liked the idea of displaying a medal of honor:

That's the best reward of all. I like that one because, see, money doesn't always last, but a plaque, you put that on your wall, and every time you come in you look at it [you think] Yes, I did that. I helped someone.

Anna also felt a medal/plaque could be valuable as a visible symbol and source of pride. Her statement was, "Well, I think that's nice. I mean you can put it up on the wall and say, 'I

donated' [laughs]." Stan referred to it as "beautiful"; Glen felt it was "wonderful." Amit liked the medal-of-honor because he believes the donor should be respected and honored.

Several patients had negative reactions to the idea of a medal of honor as a viable incentive for organ donation. These responses ranged from finding this specific reward insignificant to feeling that there was no reward that was truly going to influence an individual's decision to donate. Vick, for example, found the concept of a medal of honor trite and meaningless. "I think it's totally without meaning. What do you do? Wear it on your forehead?" Two of the negative responses seemed to come from the idea that medals were for a specific achievement such as the Olympics (like gold, silver, and bronze medals). The following exchange models this view:

Interviewer: So this next one is called a donor medal of honor. I donate my kidney, and I get like a medal that expresses [she interrupts]

Latasha: Naw!

Interviewer: How come?

Latasha: The way you said it made it sound like you're running track or something.

Martin also challenged the idea of the display, noting, "Your reward should be inside of you. I mean, not displayed, like I did this for Chevron [laughs]." Gary judged a medal of honor as a bad idea because he believed donors either are or should be beyond ego gratification. These negative responses came from not liking the reward in general as well as believing it would be ineffective as an incentive.

Preferred Status. There was considerable support (68%) for the idea of giving donors preferred status should they need an organ transplant. For some this was seen as a way of rewarding those who had donated, similar to the medal-of-honor. Silvia agreed with preferred status, saying, "I think so, yeah, because you already donated for someone else." Lee also supported the idea: "That would be good because they already sacrificed a lot. It doesn't look like the waitlists are gonna get shorter. Unfortunately. It looks like they're gonna get longer."

For the majority of dialysis patients, both those who agreed with offering preferred status and those who disagreed, the issue raised an important consideration of fairness. Amit, who is unwilling to accept a kidney from a relative for fear of what could happen to them, would have been willing to accept this donation if an arrangement like preferred status were available. He would consider such an exchange fair because it protected his relative from replacing him on a waiting list. Dorene, who did not agree with many of the rewards, liked the idea of preferred status. She reasoned that, "Because if you had not given it to me, you would have had another kidney to work with."

Most of those who said no to preferred status felt this practice would be unfair to those already waiting. Latasha said, "That's not fair at all. Because, I mean there's people on the waiting list... You were there before another person, and then their kidney fails, and they get points to go up and pass you? That's not right." Some patients felt that losing your other kidney was the risk you assumed when you made the decision to donate:

I don't think so. Because I am pretty sure they should discuss this before you commit to life decisions. That should be discussed, you know. We don't bump you up. Other people waiting, you just have to get back on the list. That's all that is. (Martin)

Four of the patients offered the same story when discussing this incentive. The story is about a man who we will call Jim, who donated a kidney to his sister who had been on dialysis. Sometime after the operation, his remaining kidney stopped working and he ended up needing dialysis. Meanwhile, the donation failed and his sister needed to go back on dialysis as well. Jim recently got a kidney transplant, and his sister is now waiting for another one herself. This story seemed illustrative for both individuals who agreed with preferred status and those who did not. Richard discussed Jim's case as a way of explaining why he thought preferred status was a good idea:

I think that's pretty good because you were nice enough to donate at first, and because of that, it affected your health, and you should get one too. Moved up a little bit. And I think that's what happened to Jim. He donated to his sister and she got well a little bit, and he was well. But eventually he had to come in here, and then his sister had to come

back. And now Jim's gone again with the new kidney. So I imagine, he got bumped up.

Stan told this story as an example of bad luck, arguing against preferred status because "I think it's the chance you take. It's the roll of the dice. And sometimes things work out the way they do for reasons. But I feel for Jim. And I felt for him." Stan recognizes the unfortunate circumstances that may cause a donor to then need a kidney, but does not see those circumstances as any different from those people already waiting for a kidney.

Funeral Expenses. A majority (80%) of the respondents agreed to offsetting funeral expenses. Most of these patients spoke of a concern for the donor's family and the concept of need. For example, Daniel demonstrated concern for the family saying, "I mean anything that'll help the family, you know, it's good. Just some kind of help for funeral expenses. Yeah." Renee said, "Yeah that one's cool. That you need it to bury." Denise qualified her positive response stressing the importance of financial need, "Well, now that'd be a good thing, providing that the person that passed away doesn't have insurance or something to bury them. So that would be a help for anyone that's in that condition." Clydell agreed with funeral expenses as an incentive qualifying only if the family could not afford the cost of the funeral and if the donor had already indicated willingness to donate organs.

Many respondents mentioned that the family would be in crisis, devastated by their loss. Anna shared her concern for the family:

I mean they're already devastated the person died. You know? And to give away an organ, I think is a big deal for the family, even if the person died. And for them to get something back... I think it's a nice thing for an organization to do.

The suggestion that the money go directly to the funeral home was mainly met with a positive response. Gary agreed with the reward of funeral expenses expressing:

I think it's showing respect for the person who took a chance and made a donation, and I know funeral expenses are a real, you know, it's a big thing that families have to deal with. I had to bury two parents. I know that it's no fun to have to go through that. So to know that that's taken care of, because someone did a good deed, and it's not a direct payment to the family. It's directly to the funeral home. I think as long as it can be managed, I think that's a great idea. It's classy.

Silvia disagreed with the idea of reimbursement for funereal expense unless the money went directly to the funeral home, to “something productive.” For Dorene, this was the only monetary reward she felt positively about, especially because it did not put the donor in harm’s way:

Now that’s a different story, because the patient is already deceased. They’re not running the risk of developing kidney failure. And needing one themselves. Again, I don’t feel that you should be paid for a kidney. But in a case like that where they need help. I could see them doing it, except the person would have to be deceased and they’re receiving help because they donated a kidney.

Of the four people who said “No” to funeral expenses, two believed that funerals should be the donor (or the donor family’s) own expense and not to be subsidized. Vick said, “No, the donor’s deceased already. He has to be buried one way or another.” Silvia also disagreed: “Not for the funeral. I don’t like that. To get money. You have to pay it for yourself.” Tanya expressed concern that offering to pay funeral expenses might encourage individuals to donate for the monetary gain. She said, “That’s a tough one. Because it starts to sound like people just wanting to make money and not necessarily give life or help someone out, but like greed. So I disagree with the last one.”

Regulated Market. Many who agreed with the idea of a regulated market (10 of the 14 positive responses) were concerned for the well-being of the poor, but felt that poverty alone did not impede autonomy. Although they did not articulate this specifically, their responses reflect the sentiment that impoverishment would not have a significant impact on one’s ability to understand the repercussions of transplantation. Tanya provides an excellent example:

...the fact still remains, everyone’s, you know, responsible for their own well being and happiness....People do it just for \$5,000 to pay off bills and stuff. Maybe if, before the process someone spoke with them about the possible outcomes, not all positive, that result from giving an organ away.

Of all nine rewards discussed in the interviews, the idea of a regulated market raised the most ambivalence. This ambivalence was often apparent within an individual’s response. Martin, Renee, Debbie and Lee all disagreed with the statement, “It should be legal to sell

organs,” but they agreed with a regulated market in organs. There was something about the market being regulated that appealed to these participants. There was more clear inconsistency within the remaining 4 yes responses. Wesley, Anna, Amit, and Gary all answered yes to a regulated market but said no to monetary rewards in general and no to legalizing the selling of organs. Furthermore, each justified their contradictory responses by explaining that the poor were particularly vulnerable. They seem to share the concern that a large incentive becomes coercive for a poor individual. The reward becomes “an offer they can’t refuse.” For example, Anna said, “They would do that [sell their organs], just because they are poor. They’re just so devastatingly poor that they’ll give up anything. Anything to get some money.”

The majority of those individuals who were opposed to a regulated market, felt that money was an inappropriate incentive, that poor people would jeopardize their health for monetary gain, and such a system would be impossible to regulate. Glen’s quote illustrates the tension between wanting a kidney and wanting to abide by his principles:

Why didn’t I do it? Well, a lot of money. But also, it didn’t feel very good. It made me feel queasy. The idea of buying an organ from somebody didn’t exactly please me. I probably could have rationalized it. Because, after all, he’d be doing it of his own free will, supposedly. But poverty doesn’t give you much free will. So that was something against it. Would I have done it? Highly unlikely. But then desperation. And I was doing this, and it worked well enough. Not very well, but well enough. It gave me survival. So would I do it? It’s a difficult moral question. I would say no, I wouldn’t have done it. I mean I have my limits. I like respecting myself. I like integrity and things like that too much.

Vick said, “Well, you can’t regulate a market like that. You’re opening the door for under the counter payments. You’re opening the door for a lot of things.”

Funeral expenses and a regulated market stand apart from the other two incentives as they have a clear monetary component. This raised important issues regarding need, greed, and the impact of poverty. Accordingly, there was inconstancy and ambivalence between these incentives and within an individual’s response. Tanya provides an excellent example. In her response to funeral expenses, she was concerned with the donor’s motivation, uncomfortable

with the idea of greed. However, she clearly felt differently in the following excerpt about purchasing a kidney:

I: Hypothetically speaking, if someone wanted to give you a kidney but wanted money in return?

R: I would be open to that.

I: What if someone was willing to give a kidney but was doing it strictly for the money?

R: I wouldn't care.

Tanya's vacillation may be an outlier, but it also speaks to the complexity of using money as an incentive, the possibility of greed as a motivating factor for donation, and the struggle with accepting greed as a motivation for the recipient as well.

Knowledge – Empathic Education and Prevention

Although not one of the nine incentives asked in the interview guide, using knowledge as a means to encourage donation was a significant finding of this study. The idea that public education about organ donation and life on dialysis would lead to more donations was generated from the dialysis patients themselves. For many of the participants, more education meant more compassion for those on dialysis and as a result, more donations:

Let them know the benefits of what organ donation can be. Let them know what the numbers are. And whether it be living donations or cadaver donations, they still do the same thing. They still give the same gift. So I think that's really important right now, is to make sure every culture fully understands that part of life is to extend life to others, to make life easier for others, make life better for others. Not just yourself. And I think that would help. (Lee)

I just think that people should be more educated about transplantation, 'cause there's not enough people giving organs...Before this happened, I would have never given up my organ before I died. Never. I would like to be cremated with everything in my system, in my body. And it's so stupid [laughs]. (Anna)

Debbie said, "See, if I'd known like I know now, yes, I would [donate]. And, you know, we don't know."

Others commented:

It might encourage a little bit, but [long pause]. It's actually more than money or financial help. It's actually the human being in society that we help each other to have the best life possible with whatever condition you have. So that kind of educational thing is very important, rather than money. (Ivan)

I think they need to have more people telling people. Let them hear about what's going on. How you could live with one kidney by helping somebody else and stuff like that. 'Cause otherwise they wouldn't know, except every now and then you hear something on television about somebody gave a kidney, but you need to spread the word about it and put it in pamphlets or whatever. (Richard)

Most people don't know that you can live with one kidney. They have no idea. My friends, who are well educated, didn't know they could live with one kidney. It's like why is it that you don't know? You wonder. But there's not that much advertisement, or not advertisement, but an educational system about transplant. (Anna)

From the above quotes, it is clear that the participants talked about the role of education differently. Some felt that education would encourage more donations by addressing misconceptions people might have about living donation. Others felt education would raise public awareness about the whole system of donation, including the organ shortage. Many talked about a type of empathic education. For these participants, knowledge about life on dialysis would encourage others to donate.

Dialysis patients also spoke of education as prevention:

I think the public should sometimes see, this is what a dialysis center looks like. And really look at it and the way people react after they're finished. Some people bounce up, walk out. But most of them don't. Most of them are so weak. And it's an educational tool so people don't have to be on dialysis. If I had seen this before, I would have really taken care of my diabetes much earlier. Much, much earlier....Because diabetes doesn't hurt, as long as you're not hurting, it doesn't feel like you're not being strangled slowly. You don't know that until you get so sick, you have no choice but coming in here. But if I knew this, and being poked in the arm twice and your arm looks like a monster, who would want that? (Anna)

I had no idea my blood issues was going to sit up there and circulate to my kidneys. And maybe if I would have known, I wouldn't have been so intense....Nutrition as well. Look at the issues that can lead to kidney failure, and do more to publicize the process to help prevent it. For everybody. And I think that would be going in the right direction. That'd be going in the right direction. (Lee)

I think more information should go out to the public about kidney disease. I think it's just kinda taken for granted as other people having it. It's like cancer. Other people get it. They don't think like, "Well, I'll get it."... Because I am sure there are ways to try to prevent it. So why not start as children? (Dorene)

Many of the participants spoke of their own ignorance of dialysis and transplant prior to starting treatment. Most of the dialysis patients said they had heard the word dialysis before, but that was the extent of their knowledge. Some suggested that it was their denial that prevented them from learning more about dialysis, while others had started dialysis in an acute setting, like the

hospital, and had no time to learn. However, many believe that dialysis and organ donation are not part of our public consciousness and they should be.

Influencing Factors

The results of this study show no direct correlation between the hypothesized influencing factors and the responses of those patients interviewed. These factors include age, gender, income, time on dialysis, transplant eligibility, donor preferences and prior thoughts on the current system of organ donation. The answers to questions about life on dialysis and talk of transplant, although interesting and informative, do not reliably predict the answers to the questions about incentives for kidney donation. It is impossible to foresee who would be in favor of or who would oppose any given incentive based on quality of life, desire for transplant, or time on the waitlist. In other words, a participant who had been on dialysis for over 5 years with a strong desire for a transplant was no more likely to say yes to an incentive than someone not interested in a transplant who has been on dialysis a shorter period of time. It is also worth highlighting that income status did not prove to correlate with a positive or negative response to the asked incentives.

DISCUSSION

It is clear from the responses to the first two domains – Life on Dialysis and Talk of Transplant – that many of the dialysis patients preferred a kidney transplant to their current life on dialysis. For many, life on dialysis is a struggle. Therefore, any change we make to our system of organ donation clearly will have a profound impact on these patients' lives. Looking at the Incentives Domain quantitatively, it appears that the majority of interviewed dialysis patients were in favor of offering incentives for kidney donation. Even the most controversial incentive – the buying and selling of a kidney in a regulated market – received 61% approval. However, when we examine the meanings attributed to incentives by participants in the interviews, it became clear that most of the patients were not actually in favor of using any of

the incentives as a means of encouraging donation. Instead, they wanted to use them as *rewards*, as a way to show appreciation and to promote fairness. To generalize, the reason why people responded yes to so many of the incentives was that dialysis patients felt that donors should be rewarded for their altruism. Most patients were reluctant to the idea of using incentives for something we should, as Good Samaritans, already be doing.

The idea of a medal of honor highlights this interpretation of incentives as rewards. Participants spoke of a desire to show appreciation for organ donation, and many saw the medal of honor as a symbol of this appreciation. People agreed with this reward because they felt that it was important to recognize and appreciate donors, not because they believed it would act as an incentive. Although it is possible to have the same symbol act to encourage donation and to reward it, it is also necessary to separate these factors, especially if offering incentives is a lower priority. It struck me that, as the central problem facing most of the patients I interviewed was the shortage in kidneys available for transplantation, these individuals were equally concerned about thanking potential donors as they were with increasing the number of donors. It would seem that if dialysis patients were excluded from the discussion of incentives because of a bias towards incentives, this assumption would have been wrong.

No one discussed preferred status as an incentive. A few patients saw preferred status as a reward, but most discussed it only in terms of fairness, both as fairness to the donor who sacrificed something and as fairness to the people waiting. Those who agreed with this incentive felt that it was fair to move prior donors ahead on the list because the sacrifice and the personal risk involved in donation entitled them to this benefit. This was viewed as the only fair way to make sure that those who donated were not at risk of being punished. Those who disagreed with using preferred status as an incentive felt that it was the waiting that entitled an individual to an available kidney, not the circumstances that led up to their kidney failure. Even though many understood and appreciated the sacrifice of donation, this did not overpower the

ingrained sense of fairness, in this case, fairness to those who wait. Simply stated, there seemed to be a notion of “first come, first serve,” and no amount of sacrifice or bad luck can alter that commitment the dialysis patients have to those who are in line.

Many patients struggled to balance the idea of money as a reward in general, the practicality and legality of a regulated market, and overall concern for the poor. Many participants were also concerned with the idea of greed as a motive. The internal conflict within some of the responses reflects an important finding: money is a unique incentive, primarily due to its differential impact on the poor. A large enough incentive leaves no choice. Some of the inconsistency in the answers to questions around a regulated market and monetary rewards, suggests that some of the participants ideally would not want a system in place where you could purchase a kidney, but if approached and with funding, they might be willing.

Raising awareness as a mechanism to increase donation was the most significant finding of this study. Although knowledge was not one of the nine incentives discussed in the confines of the interview guide, and is not discussed as an incentive in the larger debate on donation, it was the only idea the patients discussed as a method for encouraging kidney donation. This is how the lived experience shapes the debate. It is the lived experience of dialysis that places these patients in a unique position – they now know what is like to live on dialysis. This experience may not uniformly shape one’s views on the debate, but it does change one’s perspective. These patients experience dialysis as an integral part of their life – a life that they are trapped in and one that they would not wish on anyone. They see education as a way to bring the harsh reality of their experience to light. Ultimately, they believe that knowledge about life on dialysis will encourage the potential donor. The idea of increasing publicity around organ donation to generate more organs is not a new one. However, the way in which dialysis patients talk about the matter may provide more insight into what a public awareness campaign should look like.

LIMITATIONS

This sample size is small, which makes generalizability difficult. Twenty-five patients were interviewed, but there are over 300,000 dialysis patients in the United States, with over 13,000 residing in Alameda County.

There may have been selection bias. The staff helped identify potential participants in the beginning as well as when I needed help with increasing diversity among the study population. I tried to eliminate “kindness” profiling by approaching patients randomly and attending clinic frequently as well as assuring the staff that I could handle a less than friendly patient. It is possible that if this selection bias did indeed occur, I may have missed interviews with people who have very strong emotion and/or opinions about the interview content. An unbiased sample may have been richer in content, but I am not sure what that would look like. In looking over the data, I feel indebted to the study participants for their honesty and their ability to discuss a topic so close to home.

An additional limitation is the nature of the interview process. Because careful attention was not paid to specific word choice, it is possible that some of the discussion around rewards and incentives was confused by the lack of precision in the interview. Clarification between rewards and incentives was not pursued. However, it is also possible that this omission allowed for a richer discussion and for the resulting themes to surface.

CONCLUSIONS

My intention when I started this project was to discover what dialysis patients thought about various proposed incentives for organ donation, to think about how their experience on dialysis shaped those perspectives, and to use this information to inform the debate. What I learned was that dialysis patients were not as preoccupied with incentives as they were with fairness and appreciation. They prioritized their own moral values and commitments to right

and wrong based on their own ethical framework. I believe the internal conflict and ambivalence in many of the responses provides insight into the complexity and humanity of this topic. It is worth pausing here and suggesting that if dialysis patients were excluded from the debate based on the assumption that they would value incentives out of personal gain, that this assumption was found to be untrue. Dialysis patients were more interested in thinking about what was good for the donor and what was good for the patient. Although their lived experience did not predictably affect the responses to the incentives offered, it did shape the idea of empathic education.

The study participants taught me that although their experience is not part of public consciousness, there is hope for change. Although these patients might be overly optimistic, they believe that educating the population about dialysis and the impact of this life-saving treatment on their daily experience, will encourage others to donate. One potential policy implication would be to create an educational campaign using the expertise of dialysis patients, perhaps even using dialysis patients as key participants. Such a campaign would not only emphasize the risk factors for end-stage renal disease and the importance of preventative care, but also highlight life on dialysis and that although dialysis is life-saving it is also life-long. For many, life on dialysis is not an easy one. Educating the public about their experience may increase donation in a way that other public awareness campaigns have failed. Some of the dialysis patients viewed organ donation as a social responsibility. Some suggested that their sense of collective duty came after they began a life on dialysis. For them, the hope lies in our ability to empathize and act without needing to walk in their shoes – to become organ donors before we need an organ ourselves.

Appendix A – Interview Guide

Domain 1) Life on Dialysis

1. *"How did you come to be on dialysis?"*

- a. what happened
- b. why are you on it
- c. how long have you been on it

Transition

- d. was the transition to dialysis over a period of months, weeks, emergency
- e. did you feel you had time to adjust to this transition
 - do you feel you adjusted to dialysis

Familiarity

- f. what did you know about dialysis before you began
- g. did you know people on dialysis before you started
 - what did you think about it

2. *"Walk me through a typical day on dialysis."*

- a. how do you spend your time on dialysis
 - do you read, sleep, talk with people
 - did it change over time

3. *"Do you view your state of health?"*

- a. how does being on dialysis fit into that view

4. *"Would you say dialysis makes your life better?"*

- a. would you say it makes your life worse
- b. both

5. *"How has dialysis changed your life?"*

Domain 2) Talk of Transplant

For some dialysis patients, kidney transplantation is their treatment of choice.

6. *"Has the possibility of kidney transplantation come up for you?"*

- a. is this something you are interested in
- b. how far along are you in the process
 - have you been referred to a transplant center
 - have you been to the transplant center
 - have you completed a pre-transplant work-up
- c. do you have an organ donor
- d. are you on a waiting list
 - do you know how long you will be waiting

7. *"Do you think about a kidney transplant often?"*

8. *"What do you consider to be the upsides of transplantation compared to dialysis?"*

- a. what do you consider to be the downsides

Domain 3) Views of Organ Donation

9. *"Are you familiar with our system of organ donation in the United States?"*

- a. how did you learn about it
- b. what do you think of our system of organ donation
 - do you think this system works well
 - do you expect to be treated fairly by this system of organ donation

(Our current system of organ donation has been in place for over 30 years. Right now our system depends us to volunteer to donate our own organs, or on our family to volunteer to donate our organs after we die)

10. *"If you were to have an organ donated, who would you want one from?"*

- a. would you want one from a relative
- b. a friend
- c. an acquaintance
- d. someone unknown to you - a stranger

11. *"Do you have preferences for who you receive a kidney from?"*

- a. what are they
- b. do you have a preference for race or ethnicity
- c. how about a preference for someone wealthy or poor
- d. is there anyone you would not want a kidney from

12. *"Why do you think living people donate their kidney?"*

13. *"Do you think there are right reasons to donate a kidney?"*

- what are they
- a. do you think there are wrong reasons to donate a kidney
 - what are they

14. *"Organ donation is commonly referred to as a gift. Do you see it that way?"*

- a. do you think donors get something out of donating

Domain 4) Incentives for Organ Donation

15. *"Do you think people should receive some form of reward for donating a kidney?"*

- a. are there types of rewards you think should be offered

16. *"Do you think people should receive money as a type of reward?"*

17. *"Have you thought about rewards for kidney donors before today?"*

- a. would you have felt the same way about this topic before you started dialysis

I am going to ask you about some specific ideas for rewards that involve money.

18. *How do you feel about...*

a. regulated market - with a central purchasing system to provide counseling, reliable payment, insurance and financial advice. The same amount of money would be given to each donor.

b. tax credit or tax refund - for the donation of an organ.

c. reimbursement for funeral expenses – provides partial reimbursement for funeral expenses for families of deceased donors

- d. charitable contribution – a set amount of money from a donation would go to a charity of the donor's choosing.
- e. medical leave - a 30-day paid medical leave for employees who donate an organ for transplant.
- f. donor insurance - provides life and disability insurance for all living donors.

I am now going to ask you about some non-money ideas for rewards.

19. *"How do you feel about..."*

- a. donor medal of honor - would express appreciation on behalf of the American people to living donors and the families of deceased donors.
- b. preferred status – if someone donates or intends to donate (by signing a donor card), they would receive points that would increase their chance of receiving an organ from the waitlist, should they need it in the future.
- c. organ exchange - an exchange of organs from two living donors or from one living donor and one deceased donor. (Example: Joe would like Mary to get his kidney, but they are not compatible. But if Joe donates his kidney to someone else, Mary gets a kidney from the waiting list)

20. *"What do you see as the advantages of providing rewards for kidney donation?"*

- a. what do you see as disadvantages

21. *"Do you know of people receiving rewards for donating their kidneys?"*

- a. what do you think about it
 - do you agree with it

22. *"How do you feel about the following statement?"*

- It should be legal to sell your organs

23. *"Some people have been concerned that poor people will harm their health by selling their kidney for the money. What do you think about that?"*

24. *"You've expressed _____ about the purchasing of kidneys. What would make you feel differently?"*

25. *"Some people think that the human body is sacred. Do you see it that way?"*

26. *"How do you feel rewarding kidney donors would affect organ donation?"*

- a. do you think more people would donate
- b. do you think people who donate out of kindness would stop donating

Additional Thoughts

27. *"In thinking about how kidneys are donated and distributed, is there anything from your special experience as a person on dialysis that you think the public need to know?"*

- a. how about policy makers

28. *"Is there anything else you would like to add?"*

Appendix B – NVivo Codebook

1. DIALYSIS

- 1.1. Length on Dialysis
- 1.2. Original Disease
- 1.3. Transition
- 1.4. Adjustment
- 1.5. Familiarity
- 1.6. Time Spent on Dialysis
- 1.7. Illness and Health
- 1.8. Impact on Life
 - 1.8.1. Physical
 - 1.8.2. Emotional
 - 1.8.3. Lifestyle
- 1.9. Dialysis Clinic
- 1.10. Grateful for dialysis
- 1.11. Choice
- 1.12. Had I Known

2. TRANSPLANTATION

- 2.1. Interest
 - 2.1.1. Interested
 - 2.1.2. Not interestedInclude should but don't
- 2.2. Not Eligible
- 2.3. Transplant Status
 - 2.3.1. Waiting
- 2.4. Desire
- 2.5. Transplant Pros
 - 2.5.1. Freedom
 - 2.5.2. Normal
- 2.6. Transplant Cons
 - 2.6.1. Medication
 - 2.6.2. Surgery
 - 2.6.3. Rejection
- 2.7. Other People
- 2.8. Previous Experience
- 2.9. Who deserves One
- 2.10. Fear
- 2.11. Waste

3. ORGAN DONATION

- 3.1. Familiar
 - 3.2. Evaluation
 - 3.3. Donation from Who
 - 3.4. Preferences
- Include who would not want an organ from.
- 3.5. Why People Donate
 - 3.6. Reasons to Donate
 - 3.6.1. Right reasons
 - 3.6.2. Wrong reasons

- 3.7. Donation as Gift
- 3.8. Would Donate
- 3.9. Tension
- Wanting an organ but knowing that means someone has died
- 3.10. Concern for Donor
 - 3.10.1. Limits who accept from
 - 3.10.2. A story of donor
- 3.11. Actively Sought Donor

4. INCENTIVES AND COMMERCIALIZATION

- 4.1. Rewards in General
 - 4.2.1. Would reward if could
- 4.2. Monetary Rewards in General
- 4.3. Previous Thought/Heard/Read
 - 4.3.1. Heard about it
 - 4.3.2. Thought of buying/rewarding
 - 4.3.3. Attempted to buy
- 4.4. Monetary Rewards
 - 4.4.1. Regulated market
 - 4.4.2. Tax credit
 - 4.4.3. Funeral expenses
 - 4.4.4. Charitable contribution
 - 4.4.5. Medical leave
 - 4.4.6. Donor insurance
- 4.5. Non-Monetary Rewards
 - 4.5.1. Medal of honor
 - 4.5.2. Preferred status
 - 4.5.3. Organ exchange
- 4.6. Advantages of Providing Incentives
- 4.7. Disadvantages of Providing Incentives
- 4.8. Know of People
- 4.9. Should be Legal to Sell
- 4.10. Concern for Poor
- 4.11. Would Feel Differently
 - 4.11.1. Qualifiers
 - If I was sick, if it was private.
- 4.12. Human body as Sacred
- 4.13. Effects on Organ Donation
- 4.14. Appreciation
- 4.15. Money is Bad

5. ADDITIONAL

- 5.1. Tell Public
- 5.2. Tell Policy Makers
- 5.3. Like to Add

6. OTHER

- 6.1. Changed Answer, Discrepancy

Appendix C – Influencing Factors Spreadsheet

At least 7/9 N=14	Incentives M, P, F, R T, C, L, D, E	Money is the Wrong reason N=7	TOD 5 Plus Years N=9	Income Over 15,000 N=10	Income Over 30,000 N=5	Poor QOL N=7	High Desire for Transplant N=13	Not Eligible N=4	Not Interested N= 4
Tanya	YM, YP, NF, YR YC, YL, YD, YE	YT							
Vick	NM, NP, NF, NR NC, NL, ND, YE	NT							
Sylvia	YP, NF YL, YE	YC							
Cloe	NM, YP, YF, YR YE	NT							
Latasha	NM, NP, MF, NR MC, YL, ND, NE	YT							
Dwight	YM, NP, YF, NR YC, YL, ND, NE	YT							
Renee	YM, YP, YF, YR NC, NL, ND	YT							
Debbie	YM, YP, YF, YR NC, YL, YD, YE	NT							
Stan	YM, NP, YF, YR YC, YL, YD, YE	YT							
Lee	YM, YP, YF, YR NC, YL, YD, YE	YT							
Daniel	NM, YP, YF, NR YC, NL, ND, NE	YT							
Denise	YM, YP, YF, NR YC, YL, YD, NE	NT							
Richard	YM, YP, YF, YR YC, YL, YD, YE	YT							
Mary	YM, NP, YF, NR YC, YL, YD, NE	NT							
Martin	NM, NP, YF, YR YC, YL, YD, YE	YT							
Wesley	YM, YP, YF, YR YC, YL, YD, NE	YT							
John	NM, YP, YF, MR YC, YL, YD, NE	YT							
Dorene	YM, YP, YF, NC, NL, ND, YE	NT							
Betty	YM, YP, YF, YR YC, YL, YD, YE	YT							
Anna	YM, NP, YF, YR YC, YL, YD, YE	YT							
Glen	YM, YP, YF, NR YC, YL, ND, YE	YT							
Ann	YM, YP, YF, YR YC, YL, YD, YE	YT							
Paul	YM, YP, NF, YR YC, YL, YD, YE	YT							
Clydell	NM, NP, YF, NR YL, ND, NE	NT							
Gary	YM, YP, YF, YR YC, YL, YD, YE	NT							

REFERENCES

1. UNOS: United Network for Organ Sharing website: <http://www.unos.org/data>.
2. Cherry MJ. *Kidney For Sale by Owner*. 2005. Washington D.C: Georgetown University Press.
3. Brecher B. The Kidney Trade; Or, The Customer Is Always Wrong. *Journal of Medical Ethics*. 1990;16;123.
4. Reddy KC, Thiagarajan CM, Shunmugasundaram D, Jayachandran R, Nayar P, Thomas S, Ramachandran V. Unconventional Renal Transplantation in India. *Transplantation Proceedings*. 1990;22;910-911.
5. Joralemon D. Shifting Ethics: Debating the Incentive Question in Organ Transplantation. *Journal of Medical Ethics*. 2001;27:30-35.
6. Arnold R, Bartlett S, Bernet J, Colona J, Dafoe D, Dubler N, Scott G, Kahn J, Luskin R, Nathan H, Orloff S, Prottas J, Shapiro R, Ricodi C, Younger S, Delmonico F. Financial Incentives for Cadaver Organ Donation: An Ethical Reappraisal, Transplantation. 2002;73:1361-1367.
7. Jasper JD, Nickerson C, Ubel P, Asch D. Altruism, Incentives, and Organ Donation. *Medical Care*. 2004;42:378-386.
8. Goyal M, Mehta RL, Schneiderman LJ, Segal AR. Economic and health consequences of selling a kidney in India. *JAMA*. 2002;288:1589-1593.
9. Seghal AR, LeBeau SO, Youngner SJ. Dialysis Patient Attitudes Toward Financial Incentives for Kidney Donation. *American Journal of Kidney Diseases*. 1997;29;410-418.
10. Veatch RM. *Transplantation Ethics*. 2000. Washington, D.C.:Georgetown University Press.
11. USRDS: United States Renal Data System website: <http://www.usrds.org>.
12. Miles MB, Huberman AM. *Qualitative Data Analysis*. 1994. Thousand Oaks, CA: Sage Publications.
13. QSR International. *NVivo. Getting Started in NVivo*. 2002. Melbourne, Australia: QSR International.

PART 2

Reframing the Debate Adding the Perspectives of Dialysis Patients

INTRODUCTION

Although the current system of organ procurement has been in place for the last 30 years, the debate over offering incentives for organ donation continues to grow. This debate is fueled by an increasing organ shortage. As of July 2005, there were more than 89,000 people registered with the United Network for Organ Sharing waiting for organs.¹ For the largest group, the 65,000 patients awaiting kidneys, the expectation is that only about a quarter of them, that is 15,000, will receive a transplant within the next year and 6,000 will die waiting.^{2,10} The demand for kidney transplants alone has doubled in the last ten years. In 1995 the number of candidates added to the waiting list for a kidney was 17, 273 and in 2005, this number of new additions climbed to 26,806.¹ This statistic is particularly alarming as it represents the number of *new* patients waiting for a kidney and thus prolongs the average waiting time.^{1,2} The average waiting time in 1988 was 400 days compared to 1,121 days in 1999 and over 1,500 days in 2002.² The numbers swelling the waitlist continue to outpace the number of transplants, creating a sense of chasing after a rapidly moving target.

In the face of the expanding need, there is a general consensus that the current system of organ donation warrants revision. There are some who would suggest that the increase in the number of individuals added to the waitlist has more to do with the medicalization of life rather than an actual organ scarcity.^{3,4} These people would argue that the appropriate way to manage the current disparity between the number of organs needed and the number available, is to change the eligibility requirements for transplantation and thus decrease the number of people waiting. However, there are many who argue instead that this shortage demands an increase in the availability of organs, not a decrease in those eligible. This paper begins from the

assumption that organ transplantation should be encouraged. The question then becomes, “how do we promote it?” Specifically, I will explore the debate regarding incentives for organ donation.

Using the literature, I have chosen two ways of framing this debate. Altruism v. commercialization frames the debate in terms of promoting the social value of the *gift* of donation. Autonomy v. beneficence describes the debate using a philosophical structure, which emphasizes the difference between focusing on the process versus the outcome. These two dichotomies provide a way of analyzing the debate and addressing the fundamental points of contention. Using the data from Part 1, I will reframe the debate over incentives using the ethical framework of communitarianism. The debate over incentives for organ donation changes when we include the perspectives of dialysis patients. It shifts the debate from focusing on altruism and autonomy to readdressing the boundaries of our community and our roles within such a community.

LIMITATIONS TO THE DONATION MODEL & PROPOSALS FOR CHANGE

The first successful kidney transplant was performed in 1954.⁵ Over the last 50 years, doctors have learned how to transplant almost every vital organ in the human body. Advances in technology have made it possible to perform transplants on patients who were once excluded, such as those with diabetes and the elderly. The effect has been to increase the number of people eligible for transplantation. At the same time, the advent of immunosuppressive therapy has allowed for an expansion of potential donors. Today, organs are obtained from cadavers, first-degree relatives, second-degree relatives, emotionally related individuals such as spouses, non-genetic altruistic donors who have a close relationship with the recipient, and altruistic strangers.⁶

Unless a transplant is available, dialysis is the only treatment option for patients with end stage renal disease (ESRD). Without dialysis therapy these patients would die within a couple of weeks. As we saw in Part 1 of this paper, for many patients, dialysis is viewed as a necessary evil that must be tolerated while they wait for a transplant. ESRD is treated by one of three forms of renal replacement therapy: hemodialysis (60 percent of patients), peritoneal dialysis (10 percent), and kidney transplantation (30 percent).^{7,8} Advantages of transplant over dialysis make the kidney the most sought-after organ for transplantation. Kidney transplantation generally offers a longer life span and better quality of life than chronic hemodialysis.⁹ However, given the high demand and inadequate supply of available organs, not everyone who wants a kidney transplant can obtain one.

The shortage of transplantable organs has led to extensive debate over how best to procure this life-changing and often life-saving resource. The current system of organ procurement in the United States uses a donation model – people voluntarily donate their organs free from pressure or coercion. It relies on the volunteerism of uncompensated living donors and uncompensated family members of deceased donors. The problem with this system of organ donation is that it fails to meet the current need. The disparity between organs needed and organs procured has been steadily growing, creating longer waiting times and leading to more individuals dying while waiting for a transplant. Although not true for some organs, it is estimated that if all potential non-living kidney donors became actual donors, the supply of cadaveric kidneys could accommodate the number of new patients added to the waiting list and help to reduce the current backlog.¹⁰ It is important to note that this estimate is based only on the number of cadaveric donors and does not include living donors. One could only imagine the potential impact of more living donations.

Still, this leaves us with the question: why does the donation model fail to live up to its potential? The simple answer is two-fold. First, not everyone who might be willing to donate is

informed about the need. As we learned from the dialysis patients in Part 1, organ donation is not something people know a lot about. Second, not all those who are willing to donate actually do. We know, for example, that half the population would be willing to donate, but only 30% have signed an organ donor card.⁵ In his book, *Transplant Ethics*, Robert Veatch concludes that this problem is one of inertia. In our current system, individuals are required to purposefully and actively indicate their choice to donate. This creates a burden on the individual to become an organ donor or the next-of-kin to make this decision in a moment of crisis. People do not bother to become organ donors because organ donation is not at the forefront of our consciousness, especially at a time of tragedy. Planning for the disposal of one's body parts is not a pleasant subject and dying in a manner that would make organ procurement possible is not very common. Compounding this problem is the fact that even if someone indicates their preference to donate, the family retains the right to ignore their wishes. When family members are asked to donate on behalf of the deceased, 50% of them refuse irrespective of the individual's predetermined choice.⁵

Although the situation sounds bleak, progress has been made. Rates of identification of potential donors and referral to organ procurement agencies have increased over the last decade.¹¹ Rates of consent and transplantation (also known as conversion) have increased as well.¹¹ Online donor registries now allow people to record electronically their desire to donate. Government based registries are also linking up with motor vehicle departments so that the question of donation is presented at the time of obtaining or renewing a license.¹² Yet the problem with any registry system that simply asks "yes" or "no" is that the critical component of education continues to be overlooked – thereby making the decision frequently uninformed. For individuals who know little about donation or transplant, the overwhelming tendency is to decline.⁵

Meanwhile, living organ donation has become much more common. In fact, many dialysis patients are circumventing the long wait by seeking living unrelated donors through public solicitation. Public solicitation for organs raises interesting ethical concerns. One objection is that the practice might be unfair. Those who have the most compelling stories and the means to advertise their plight would get organs before others who may be in greater need. Public solicitation also opens the door for directed donation, in which a person indicates preference for the *type* of recipient. Some argue that just as we have the right to donate to the political parties and charities of our choice, so should we be able to choose to whom we give our organs.¹³ The most ethically problematic cases are those in which the recipient is chosen on the basis of race, religion, or ethnic group. To address the growing trend of living donation, an internet site called, MatchingDonors.com emerged in 2004.¹⁴ This website provides a vehicle for individuals to solicit and match with potential live donors and represents the failure of the donation model to adequately address the organ shortage. Individuals are now using the internet to go beyond the traditional donation model to explicitly petition for donations.

Clearly there is a need to readdress the donation model. To generalize, there are two different approaches to modifying the donation model. First, there are proposals that work within the current structure to improve the system of asking and educating. For example, such policy changes would emphasize national education programs devoted to the benefits of transplantation and the pressing need to donate organs.² Another method of improvement, while working within the system, could include requiring physicians to ask families to donate organs from recently deceased relatives or requiring all citizens to register their preference with regard to organ donation, “mandating choice.”^{2,15} Our current system requires that people voluntarily opt into the system of donation. Another method of increasing the supply of organs would require that individuals actively opt out of the system. The idea is that if we can presume the consent of the deceased, there will be a substantial increase in the yield of organs. For those

individuals who do want their organs procured after death (social surveys suggest about half the population)⁵ they would have to opt out of the system. The above measures of increasing donation do not affect the individual's motivation.

Second, there are numerous proposals to increase donations by offering incentives. Some incentives provide public recognition for the donation. A donor medal-of-honor would express appreciation on behalf of the American people to living donors and the families of deceased donors. Other incentives affect the order of the waitlist. For example, preferred status gives "allocation points" to the donor, allowing them to move up on the waiting list should they need an organ in the future. In the case of organ exchange, a living donor who is unable to donate to their loved one, donates instead to a compatible patient on the waiting list in exchange for moving their intended donor higher on the waiting list. This exchange permits two transplants to be performed in circumstances that would otherwise have permitted neither. Finally, there are incentives that offer indirect or direct financial compensation. These range from reimbursement for funeral expenses to offering tax credits and most controversially, creating an open, unregulated market to govern the supply and distribution of organs.¹⁶

Although working within the system has potential to expand donations, the discussion of incentives speaks to the possibility that the current shortage demands a different approach. In other words, that the failure of the donation model is perhaps not simply a failure in implementation, but also a failure to recognize the limitations of volunteerism.

THE DEBATE ON INCENTIVES FOR ORGAN DONATION

As discussed above the debate on incentives for organ donation encompasses a variety of incentives, some monetary and some not. However, in order to analyze the fundamental arguments underpinning this debate it is helpful to look at two extremes – an open, regulated market versus our current system of pure altruistic donation. Although an unregulated market is

the absolute extreme on the side of commercialization, I chose not to use it because it is not a widely supported idea in the literature, even among proponents of kidney sales.

A number of perspectives from the fields of anthropology, economics, bioethics, medicine and policy have entered the debate of kidney commercialization.² Prior to 1984, individuals offered their kidneys for sale through advertisements and other publicly available means. During this period, the asking price for kidneys ranged from \$5,000 to \$160,000, depending on the financial circumstances of both the buyers and the sellers.¹⁷ Congress then passed The National Organ Transplant Act (NOTA), a law that prohibits the sale of organs and body parts for purposes of transplantation.^{17,18} The passage of NOTA was influenced by an attempt by Dr. Barry Jacobs to create the International Kidney Exchange to broker the sale of organs obtained internationally.¹⁹ The public did not react favorably to Dr. Jacob's entrepreneurship and Congress responded with the passage of NOTA, arguing that the sale of human organs diminishes the dignity of human beings. This Act calls for penalties of up to 5 years imprisonment and up to \$50,000 in fines for anyone found buying or selling human organs.¹⁸ The overall consensus was to preserve the altruistic donation model and to avoid the commodification of the human body. This was based on the argument that organs should be considered gifts of extraordinary magnitude, not merchandise.

Although our system of donation has not changed significantly, the debate over incentives has evolved. Twenty years ago there may have been a consensus favoring altruism above all else, but over the last two decades the continued shortage has led many toward readdressing the issue of incentives. Over time, moral grips have loosened. As Veatch suggests,

A well-presented argument in favor of markets for organs is more subtle and difficult to refute...Assuming that the vendor is an adult who is mentally competent and has been informed adequately about the risks and benefits of selling a kidney and assuming that person, after careful consideration, comes to the conclusion that it is better to sell the kidney and do something with the money, why should our society prohibit such sales? It cannot be that such persons have always calculated their interests incorrectly.

This trend is still met with resistance. Many remain committed to the ideal of altruism and argue that any incentives taint the nature of the donation. In his essay, *Shifting ethics: debating the incentive question in organ transplantation*, Donald Joralemon notes the importance of exercising caution when advocating for commercialization.¹⁹ He suggests, “The care with which advocates are proceeding shows they recognize that the public is not clamoring for a reversal of the prohibition against financial incentives.” There remains significant opposition to incentivizing donation. Both sides of this debate have well-grounded ethical, philosophical, and practical motivations that underlie their views.

Altruism vs. Commercialization

Our current system of organ donation is based in the assumption of altruism on behalf of the organ donor. An altruistic action is defined as motivated by the concern for the needs of others: it is freely chosen and not required by duty or obligation. The individual is not subject to manipulation or exploitation.²⁰ The Transplantation Society guidelines for the distribution and use of organs require that donors be altruistically motivated:

It must be established by the patient and transplant team alike that the motives of the donor are altruistic and in the best interests of the recipient and not self-serving or for-profit...especially in the exceptional case where the emotionally related donor is not a spouse or a second degree relative, the donor advocate would ensure and document that the donation was one of altruism and not self-serving or for-profit.²¹

Altruism is therefore a requirement for donation. Its value is explicitly stated in the goals for transplantation.

It is in valuing altruism and the voluntary nature of the exchange that we refer to organ donation as the “gift of life.” A market in organs, therefore, would corrode the gift sentiment. Not only would the gift—in this case, the kidney—lose value, but so would the exchange. The same argument was applied to the sale of blood in the seventies. Richard Titmuss argued that, “individuals should provide blood out of altruistic solidarity, out of fellowship between one human being and another, rather than out of self-interest.”¹⁷ Placing a cash value upon the gift

would diminish the act of altruism, and this act serves to unite society. In his evaluation of the voluntary British model of blood donation, Titmuss observed:

As individuals they were, it may be said, taking part in the creation of a greater good transcending the good of self-love. To “love” themselves they recognized the need to “love” strangers. By contrast, one of the functions of atomistic private market systems is to “free” men from any sense of obligation to or for other men regardless of the consequences to others who cannot reciprocate, and to release some men (who are eligible to give) from a sense of inclusion in society at the cost of excluding other men (who are not eligible to give).²²

Today, blood is almost universally donated with only a small percentage purchased. Although there were very practical reasons for the transformation of the blood system in the United States, such as paid blood having higher rates of infection, Titmuss’s work is said to have had a profound effect.²² His arguments stood the test of time and are often applied to the debate on organ commercialization. Altruistic organ donation builds collective solidarity.

Supporters of kidney commercialization argue that it is naïve to think that *all* donations are purely altruistic. The emotionally-related donor provides an excellent example. A body of transplant literature is devoted to discussing this population of donors, their motivations to donate and the responsibility of the transplant profession to understand them. Although many people in this group of donors, which includes spouses, friends, and family members, donate altruistically, many people donate under the guise of altruism. Some donors find redemption in their gift, while others see it as a form of collective responsibility, a duty. Are these invalid reasons to donate? Do the alternative motivations outweigh any altruistic component in the gift? Would we let them donate knowing that they are not acting truly altruistically? Can any act be completely altruistic? One may argue that donating to a family member is simultaneously selfless and selfish. It serves the interests of the recipient as well as the interests of the family. Loved ones may not necessarily want, or be able to, separate their interests. The distinction between self-interest and altruism ultimately makes no sense in this context. The need to balance selfishness and altruism might be considered a universal feature of family relationships.²⁰ Intimacy allows living donors to take on the risk of transplantation, believing it

was their obligation to assume such a risk.²⁰ Family is not the only source of this obligation. External pressure to donate can come from one's religion, values, priorities and any other life-guiding forces.

The pressure to donate is recognized by the transplant community. Living-donor transplantation requires third parties, the involvement of physicians and other transplant center personnel. These mediators serve as moral agents in decisions of transplantation, especially when family members feel pressure to donate against their will. The surgeon shares moral responsibility in the decision to donate because he or she must agree to perform the surgery. For example, to prevent families from pressuring unwilling members into donating their organs, surgeons may protect the potential donor by saying that he or she is not eligible, providing what seems to be a medical excuse.¹³ Although it may be strictly true, it is deceptive. The reason the person is not eligible is that he or she has declined in the presence of the doctor. Thus, there are competing motivations for donation that although do not discount the possibility of altruism as a guiding force, do at the very least influence the decision to donate.

Those who argue for commercialization contend that given the multiple motivations for donation, adding financial incentives does not inherently change the emphasis on altruism. Instead, financial incentives are just one of the many competing factors that may or may not influence an individual's decision to donate. Those who argue against commercialization maintain that financial incentives corrupts the exchange, diminishing the possibility of an altruistic donation. The debate between altruism and commercialization emphasizes the potential impact of financial incentives and recognizes the possibility that monetary incentives are ethically different when compared with other motivations like familial obligation or religion.

As we saw in Part 1, most dialysis patients did not favor using any of the incentives as a means of encouraging donation. Instead, they wanted to use them as *rewards*, as a way to

show appreciation and to promote fairness. To generalize, the reason why people responded yes to so many of the incentives was that dialysis patients felt that donors should be rewarded for their donation. However, most of the dialysis patients did not demonstrate a strong concern for the idea of pure altruism.* Instead, many patients spoke of organ donation from a communitarian line of reasoning. For example, many of the patients were unenthusiastic about the idea of using incentives because they did not understand why we should offer incentives for something we should, as Good Samaritans, already be doing. For communitarians, organ donation may be viewed as a social value and therefore, donating organs is part of our social responsibility within a community with this social value. Although dialysis patients appreciate the altruism with which many donors make their gift, there is still a sense that donations are part of our collective responsibility – something we are required to do when compatible with our own health. The communitarian duty to donate is a stronger obligation than that of altruism, which can never be required.

Autonomy vs. Beneficence

Autonomy is a complex and crucial ethical doctrine. Utilitarians use this concept as a means of producing welfare; giving individuals choice is a way to maximize social good. For Kantian and other autonomy deontologists autonomy is valuable even when it conflicts with welfare. Autonomy respects our capacity for self-determination for acting according to reason. An autonomous action is made with intention, with understanding and without controlling influences that determine the action.²³ In practical terms, autonomy forms the basis for informed consent. In the medical setting, the concept of autonomy is the reason we respect patient choices.

* Although not addressed in Part 1, dialysis patients were asked why they thought people donated their organs and if there were right and wrong reasons to donate.

Nikola Biller-Andorno and colleagues discuss autonomy in the situational and relational context of organ donation. They suggest that although it is commonly agreed that coercion invalidates autonomous choice, the influence and effect of emotion and relationships on the capacity for autonomous choice is controversial.²⁴ In the discussion of altruism and commercialization, the issue of alternative motivations was discussed. Using autonomy to frame this same dilemma, the issue focuses not on the existence of other motivating factors but whether these other motivations are coercive.

In the debate on kidney commercialization, financial incentives are seen as the potentially coercive factor. Those opposed to kidney sales argue from a place of beneficence. In focusing on the outcome rather than the process, they maintain that it is important to restrict the choice of the potential donor/seller in order to protect them from harm. There are those who question the ability of poor individuals to make an informed decision about donation in the presence of the coercive influence of poverty. By definition, coercion undermines the voluntariness requirement. When the financial need is so great that the offer of money alters the decision, autonomy cannot be realized, the decision is not entirely free and voluntary. In the situation of poverty, the need may be so overwhelming that it prevents other factors, such as one's personal health, from weighing significantly. Opponents of kidney commercialization argue that these impoverished individuals need to be protected from the powerful influence of financial incentives. Lawrence Cohen, an anthropologist studying the kidney trade in India, describes a typical story from the women he interviewed:

I sold my kidney for 32,000 rupees. I had to; we had run out of credit and could not live. My friend had had the operation and told me what to do. I did not know what a kidney was; the doctors showed me a video. It passes water; it cleans blood. You have two. You can live with one, but you may get sick or die from the operation or from something later. You have to have the family planning operation because without a kidney childbirth is very dangerous. I already had that operation.²⁵

It is clear the woman in the above quote was motivated by poverty. The line, "could not live" is particularly powerful. Although she received some information regarding the surgery, she was

limited in her ability to make an autonomous choice because of that line. She felt she was without options.

Opponents of kidney sales argue that regardless of whether or not a poor individual is free from financial coercion, they should be protected from their own decision to sell their kidney as there is limited evidence to show any long-term benefit. Moreover, the short-term benefit may not even be realized. A recent study performed by Madhav Goyal et al. in India demonstrated that among paid donors, selling a kidney did not lead to a long-term economic benefit and may have been associated with a decline in health.²⁶ This study also demonstrated that many recipients did not receive all of their funds. Middlemen and clinics promised more than they actually paid. Decisions to sell a kidney appear to have less to do with raising cash toward some current or future goal than with paying off high interest debt to local moneylenders. Sellers were frequently back in debt within a few years.* Beneficence can thus be argued in the context of protecting the individual from harm and at times must override autonomy.

By prohibiting the sale of kidneys, we have made a choice for people in very desperate situations, hoping our decision was for their own good. Proponents of kidney sales argue that the risk from focusing on the outcome, instead of the process, is that implicit assumptions are made about people living in poverty. For example, if wealthy people are free to engage in dangerous sports for pleasure, or dangerous jobs for high pay, should the poor who take on a potentially lesser risk of selling a kidney for greater rewards be thought so misguided as to need saving from themselves?¹⁷ Does their financial need really make these impoverished individuals' choices invalid?

* It is also important to note that it has been argued that a market in organs will exacerbate the inequalities between the rich and the poor: in an organ market, the poor will not be able to buy and the wealthy will have no need to sell.

Those who argue for commercialization maintain that financial desperation is not inherently coercive—poor individuals can make an autonomous choice to sell their kidney and should be allowed that option. Philosophers have argued that the capacity for choice gives human beings moral value and thus should be respected as a means of respecting human dignity. Immanuel Kant is used in this context to support the idea that the “unconditional worth” of an individual lies in the ability to determine one’s own destiny.^{27,28} Arguing that poverty changes one’s capacity for autonomy can be viewed as an assault on the dignity of this already vulnerable population. If the poor are incapable of autonomous choice they have lost what makes them human. Interestingly, both sides of this argument aim to respect the impoverished. Those who argue against commercialization insist that in order to protect the dignity and well being of this population, society must prohibit the sale of kidneys. Those who argue in favor a regulated market contend that allowing these individuals the choice is the only true means of ensuring their dignity and respect. For proponents, the process is more important than the outcome.

In addition, many supporters of kidney sales hold the libertarian view that the autonomy rights of individuals are paramount. Using this framework, the debate is not about whether poverty influences autonomy but rather more simply that autonomy is the social value that always outweighs all others. Autonomy encompasses all personal choices, including the ability to sell one’s body or organs. This right to sell an organ from their own body enables individuals to dispose of a valuable commodity that belongs to them. Viewing their body as a commodity is their right, as is what they do with that commodity. Thomas Shannon describes organ commercialization from the perspective of *utilitarian individualism*:

It could fit into my goal of maximizing my financial interests. And such a transaction would be relatively clean – no troublesome emotional entanglements, no need for follow-up on how the individual is doing, no need to think about the other at all, actually. The recipient got what he or she wanted and I got what I wanted. Tit-for-tat; clean and simple. What more could one want?²²

A market in kidneys is the logical consequence of a social structure that values individualism and liberty above all else. At the limit, paternalism is never justified.

Opponents of a market in organs argue that society has a moral obligation to restrict autonomy when the actions of individuals hurt themselves or others. As a society, we have a body of generally accepted values, of which autonomy is only one. In her article arguing against kidney sales, Cynthia Cohen states:

Even in a just democratic polity, there may be justification for public limits on commercial exchanges that are grounded in publicly accepted fundamental values, even though such limits have the effect of limiting individual liberty. The law is directed toward preventing others from invading their bodies without their permission, that is, from what is known in legal parlance as “battery.”¹⁷

There are many laws that restrict the freedom of individuals with regard to uses of their own bodies, such as those against prescription of Schedule 1 drugs, pornography, prostitution, and voluntary servitude.¹⁷ These restrictions are based on the idea that there is a public reason, which outweighs allowing individuals to make their own decisions.

Communitarian theory may be useful in this discussion of autonomy. Communitarians argue that personal autonomy is better achieved within the community than outside communal life.²⁹ Authors Shlomo Avineri and Avner De-Shalit suggest, “the community is a good because only by virtue of being members in communities can we find a deep meaning and substance to our moral beliefs.”²⁹ Communitarianism has the potential to combine community with a commitment to basic liberal values. In addition to valuing the liberal notion of autonomy, we may also value communal ideals such as helping others.

As we saw in their responses to the preferred status incentive, dialysis patients demonstrated great concern for the well being of both the donor and the recipient. Most patients discussed preferred status in terms of fairness. By ‘fairness’ to the donor who sacrificed their kidney and by fairness to the people waiting in line, dialysis patients expressed a communitarian concern for the well being of both parties involved. Their sense of community extended beyond the walls of the dialysis clinic. Through their suggestion of empathic

education, it is clear that dialysis patients believe they participate in a community with the social value of helping each other. However, they also believe that within this community, autonomy is also a value, and the choice to donate should be that of the individual.

Communitarianism theory has the potential to integrate both autonomy and beneficence, to focus on the process and outcome simultaneously. The idea of social responsibility does not necessarily restrict freedom, but it suggests that we owe each other more. Dialysis patients never said that people must donate. But it was clear that they believe people should and would donate if they knew more about the struggle of our fellow members of society. Receiving kidneys from desperate, impoverished individuals is problematic because it would decrease the donor's well being. Rather expecting donation as part of communitarianism means more obligations to those who donate and to those who receive.

THE CURRENT REALITY OF ORGAN TRANSFER

Up to this point, I have discussed the donation model and the arguments for and against commercialization primarily in theoretical terms. In reality, several practical factors influence the debate. For example, the existence of black market in organs presents a public health dilemma and an immediate, practical point of contention. Given that such a market persists, is there more harm done in ignoring it and condemning it than in recognizing its presence and working to regulate it? Some argue that we have a duty to regulate the potentially coercive and dangerous commerce in kidneys, regardless of whether or not its existence is ethical.³⁰

Establishing a regulated market would enable, "authorities to monitor developments and react efficiently when the need arises to prevent indecent price escalation that puts organ donors at mercy of affluent buyers."³¹

A legalized system would protect donors from unscrupulous middlemen whose sole interest is profit making and ensure that the organs are sourced legitimately... With a legalized, well-controlled LUR [living unrelated] renal transplant program, any

patient's death might be avoided. The great burden of dialysis expenses would be relieved and quality of many patients' lives improved.³¹

Others argue that no amount of screening or control could prevent donors and recipients from exploitation. It is a system that cannot be regulated.² Still as one transplant surgeon, K.C.

Reddy, indicates

To dismiss the idea of paid donors as the ethics of expediency is to deny these patients the right to live. We serve only the corrupt and the unscrupulous if we deny the patient benefit of a transplant that is medically indicated because of our fear that the paid donation process is too complicated to be regulated.³⁰

The fact that a monetary trade exists—despite the decades of debate—indicates a need to put aside the theoretical discussion and address the immediate situation.

Along similar lines of focusing on the reality of organ sales, the severe poverty, which motivates individuals to sell their kidneys, cannot be ignored. Some have argued that a regulated market offers a potential, short-term solution to the problem of poverty.³² An analogous argument has been made for the continued use of sweatshop labor. The poor working conditions, low wages, and exploitation of sweatshops make them difficult to support, however, they may be the only opportunity offering immediate help to this needy population.³³ For those living in poverty and willing and wanting to sell their kidney, issues of autonomy and social values are trivial compared to getting food and paying their debts. To ignore these concerns and dismiss the idea of commercialization without consideration for the practical implications of this policy decision is irresponsible and perhaps equally unjustified. From a communitarian perspective, the immediate situation warrants our attention. We have a duty to help those who are in desperate need – the people who currently sell their organs, and the people who suffer while waiting for one.

CONCLUSIONS

In Part 1 of this paper, we learned that dialysis patients were not as preoccupied with incentives as they were with appreciation and fairness. In talking about the incentives of

preferred status, dialysis patients showed concern not only for their fellow dialysis patients waiting in line for a kidney, but also for the potential donor who was willing to assume the risk of donation. Dialysis patients also demonstrated concern for the potential donor when motivation to donate came from a place of vulnerability (i.e. desperate poverty). The idea that communitarianism may be useful in the debate of incentives became clear when dialysis patients discussed educating the public about organ donation, and more importantly, life on dialysis. They believe that by bringing their harsh reality of life on dialysis into public view, more people would donate their organs. Dialysis patients believe we have a duty to help each other in a time of need.

The debate over incentives for organ donation changes when we include the perspectives of dialysis patients. Their influence shifts the debate from a focus on incentives to readdressing the boundaries of our community and our roles within such a community. We know that many people are willing to donate, but have never had the resolve. Furthermore, we know that many people just do not know enough about it. Instead of focusing on incentives, we might want to find a way to bring ourselves to be concerned enough about our fellow citizens whose well-being hang in the balance.

REFERENCES

1. UNOS: United Network for Organ Sharing website: <http://www.unos.org/data/>
2. Cherry MJ. *Kidney For Sale by Owner*. 2005. Washington D.C: Georgetown University Press.
3. Scheper-Hughes N. The New Cannibalism. *The New Internationalist*. 1998;14-17.
4. Kuczewski MG. The Gift of Life and Starfish on the Beach: The Ethics of Organ Procurement. *The American Journal of Bioethics*. 2002;2:53-56.
5. Veatch RM. *Transplantation Ethics*. 2000. Washington, D.C.: Georgetown University Press.
6. Kaplan BS, Polise K. In Defense of Altruistic Kidney Donation by Strangers. *Pediatric Nephrology*. 1998;14:518-522.
7. Gordon EJ. They Don't Have to Suffer for Me: Why Dialysis Patients Refuse Offers of Living Donor Kidneys. *Medical Anthropology Quarterly*. 2001;15:245-267.
8. United States Renal Data System website: <http://usrds.org>
9. Gordon EJ. Patients' Decisions for Treatment of End-Stage Renal Disease and Their Implications for Access to Transplantation. *Social Science & Medicine*. 2001;53:971-987.
10. Steinbrook R. Public Solicitation of Organ Donors. *New England Journal of Medicine*. 2005;353:441-444.
11. Sheehy E, Conrad SL, Brigham LE, Luskin R, Weber P, Eakin M, Schkade L, Hunsicker L. Estimating the Number of Potential Organ Donors in the United States. *NEJM*. 2003;349:667-674.
12. Donate Life California Organ and Tissue Donor Registry website: <http://donatelifecalifornia.org>.
13. Truog RD. The Ethics of Organ Donation by Living Donors. *New England Journal of Medicine*. 2005;353:444-446.
14. MatchingDonors.com website: <http://www.matchingdonors.com/life/index.cfm>.
15. Delmonico FL, Arnold R, Scheper-Hughes N, Siminoff LA, Kahn J, Younger S. Ethical Incentives – Not Payment – for Organ Donation. *NEJM*. 2002;346:2002-2005.
16. Rothman DJ. Ethical and Social Consequences of Selling a Kidney. *JAMA*. 2002;288:1640-1641.
17. Cohen, Cynthia B. Public Policy and the Sale of Human Organs. *Kennedy Institute of Ethics Journal*. 2002;12:47-64.
18. United States Public Laws, 98th Congress-Second Session-National Organ Transplant Act, 1984.
19. Joralemon D. Shifting Ethics: Debating the Incentive Question in Organ Transplantation. *Journal of Medical Ethics*. 2001;27:30-35.
20. Ross LF, Glannon W, Josephson MA, Thistlewaite JR. Should All Living Donors Be Treated Equally? *Transplantation*. 2002;74:418-426.
21. The Transplant Society website: <http://www.transplantation-soc.org>.

22. Shannon TA. The Kindness of Strangers: Organ Transplantation in a Capitalist Age. *Kennedy Institute of Ethics Journal*. 2001;11:285-303.
23. Beauchamp TL, Childress JF. *Principle of Biomedical Ethics*. 3rd Ed, 1989. NY: Oxford University Press. 67-119.
24. Andorno N, Agich G, Doepkens K, Schauenburg. Who Shall be Allowed to Give? Living Organ Donors and the Concept of Autonomy. *Theoretical Medicine*. 2001;22:351-368.
25. Cohen L. Where it hurts: Indian material for an ethics of organ transplantation. *Daedalus*. 1999;128:135-165.
26. Goyal M, Mehta RL, Schneiderman LJ, Segal AR. Economic and health consequences of selling a kidney in India. *JAMA*. 2002;288:1589-1593.
27. Kant I. *Groundwork of the Metaphysics of Marals*. New York: Harper and Row; 1964.
28. Kant I. *The Doctrine of Virtue, Part II of the Metaphysics of Morals*. New York: Harper and Row; 1964.
29. Avineri S, de-Shalit A. *Communitarianism and Individualism*. 1992. New York: Oxford University Press.
30. Reddy KC, Thiagarajan CM, Shunmugasundaram D, Jayachandran R, Nayar P, Thomas S, Ramachandran V. Unconventional Renal Transplantation in India. *Transplantation Proceedings*. 1990;22:910-911.
31. Larijani B, Zahedi F, Ghafouri-Fard S. Rewarded Gift for Living Renal Donors. *Transplantation Proceedings*. 2004;36:2539-2542.
32. Radcliff-Richards J, Daar AS, Guttman RD, Hoffenburt R, Kennedy I, Lock M, Sells RA, Tilney N. The Case for Allowing Kidney Sales. *The Lancet*. 1998;352:1950-1952.
33. Brecher B. The Kidney Trade: or, the Customer is Always Wrong. *Journal of Medical Ethics*. 1990;16:120-123.

